

# **HIV/AIDS**

## **WORK GROUP ON HEALTH CARE ACCESS ISSUES**

for Women

Office of Minority Health  
Resource Center  
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U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES  
Public Health Service  
Health Resources and Services Administration  
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## **Background - The Ryan White CARE Act and Access Work Groups**

**I**n response to the critical need for additional resources to provide medical and support services for people living with HIV and AIDS, Congress passed the Ryan White Comprehensive Resources Emergency (CARE) Act of 1990. The CARE Act, which became law on August 18, 1990 and received its first appropriations in November, 1990, has one overriding objective, "...to provide grants to improve the quality and availability of care for individuals and families with HIV disease..."

Titles I and II of the CARE Act are administered by the Bureau of Health Resources Development (BHRD), a part of the Health Resources and Services Administration (HRSA). These titles direct grant funds to metropolitan areas most heavily affected by the HIV epidemic (Title I) and to all States and U.S. territories (Title II). These grants are used primarily to fund ambulatory, outpatient, and community based care, encompassing both medical and social support services, for those individuals and families with HIV and AIDS who are not insured through either government or private sources or who lack critical services.

Two basic tenets of the CARE Act are:

- (a) that people and communities affected by the HIV epidemic be included in planning, prioritizing, and managing the provision of care, and
- (b) that the comprehensive care needs of individuals with HIV and AIDS be met through a continuum of planned and coordinated services.

Despite these tenets and the requirements of the CARE Act, BHRD recognizes that there are barriers that limit or prevent underserved populations from receiving and, in some cases, even from seeking, access to care. Many of these barriers existed before the HIV epidemic; most have been highlighted and or exacerbated by it.

In order to identify these barriers and to begin to develop plans of action for overcoming them, the Bureau began a series of Work Group meetings in 1991. The Work

Group meetings were developed to assist BHRD in defining the complex issues that influence use of HIV care and understanding clients' perceptions about the availability and accessibility of specific medical and support services. The Work Group discussions were planned to focus on the difficulties faced by underserved populations with HIV disease: those people whose ethnic, racial, economic, gender, or cultural backgrounds differ from those of the population traditionally served by the medical clinics and social support agencies providing the majority of HIV-related services. Each meeting addresses the critical access issues for one particular population.

The goal of these meetings is to define the difficulties these populations face and to identify strategies for ensuring that appropriate CARE Act services are made available to and are utilized by them. In addition, some specific objectives for each Work Group are to:

- develop priorities for evaluation research and specific evaluation projects designed to better understand the real and perceived barriers faced by unserved and underserved populations needing HIV / AIDS services;
- compile a bibliography on barriers to HIV / AIDS care and related health services research;
- identify health services researchers working on HIV / AIDS related topics;
- identify members of the affected population, as well as individuals who deliver health care and support services, who can serve as consultants and help identify priority issues for evaluation and follow-up.

The Work Groups also produce recommendations on specific mechanisms, including technical assistance from the Bureau, for addressing the critical needs identified in their discussions.

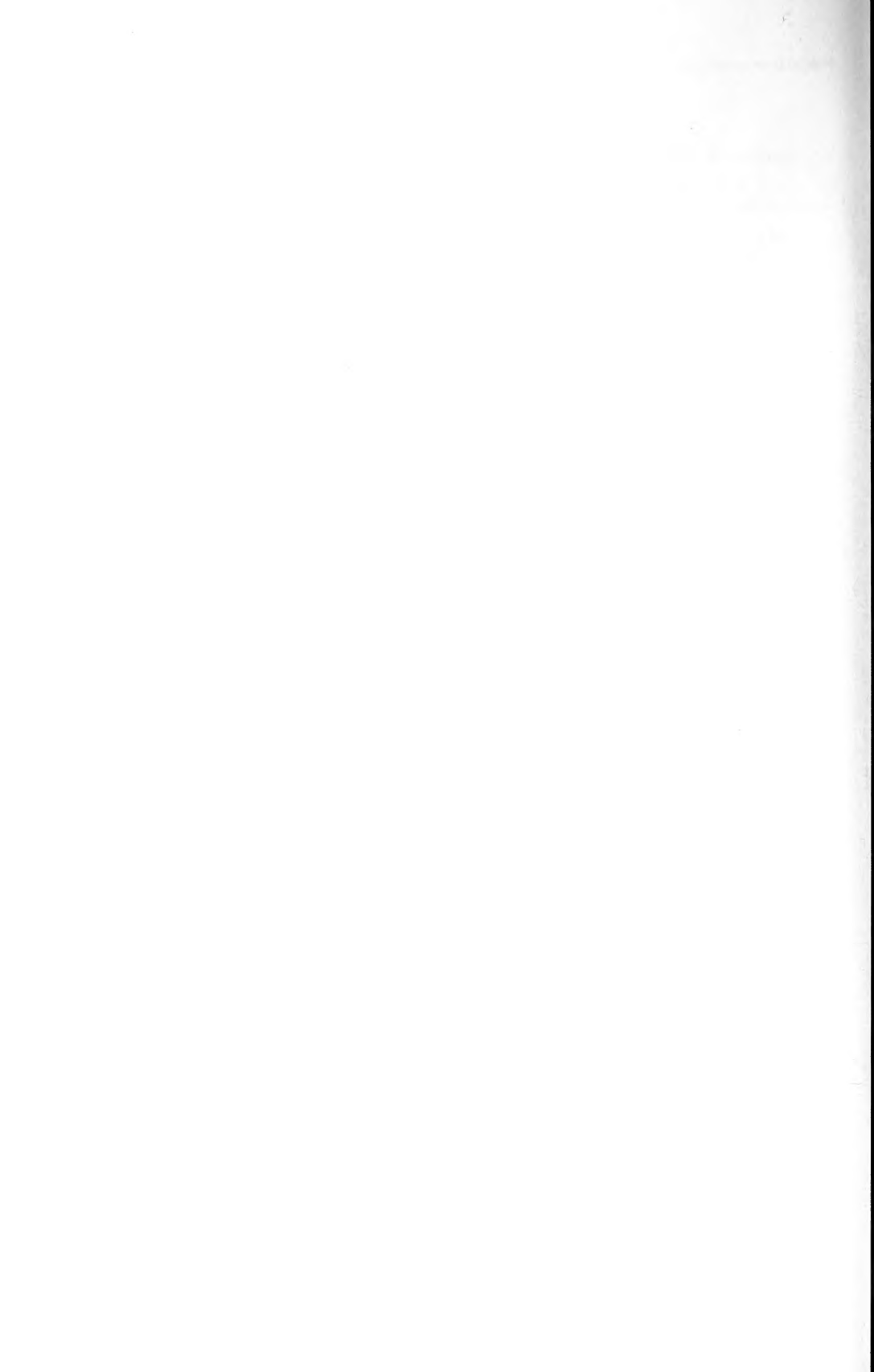
Each Work Group is composed of between 10 to 20 invited participants who are members of the ethnic, minority, or special population being addressed; they include service providers, people living with AIDS, and health services researchers. Work Group meetings are one and a half days in length, are moderated by BHRD staff, and are structured along informal lines to allow for creative thinking and in-depth discussion.

At least seven Work Groups on access to HIV services will be held through 1993. Four groups already have met;



they have discussed the special access to care issues pertaining to: African Americans; Hispanic Americans; Women; and American Indians. Three additional Work Groups are planned: one on gay men, including gay men of color; one on Asian Americans; and one on substance abusers. This report focuses on the discussions, findings, and recommendations of the Women's Access Work Group, held February 27 and 28, 1992. BHRD invited women with HIV, service delivery professionals working with female clients, and health services researchers with expertise in HIV and women's health to participate in the group. The meeting was moderated by BHRD staff members Gloria Weissman, Special Assistant to the Director, BHRD, and Moses B. Pounds, Ph.D., Senior Staff Fellow, Office of Science and Epidemiology. Other individuals from the Federal and private sectors with an interest in HIV and women's health attended the final session of the meeting, during which proposed study designs and general recommendations were presented.

The Work Group's recommendations have been distributed for review and comment to the participants and will be disseminated to Title I and II CARE Act grantees prior to the development of a final evaluation and program agenda. We view these Work Group meetings as the beginning of a collaborative learning process among HRSA, its grantees, and the people with HIV disease they are dedicated to serving.



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## **Introduction: Women's Access Work Group**

A number of important national meetings have been convened in the past two or three years to define the major issues relative to women and HIV and to make general recommendations regarding research needs in this area. This Work Group was designed to build on the results of those earlier meeting. Its focus was on setting priorities for evaluation research in the specific area of access to care for HIV positive women and on developing detailed proposals for implementing that research agenda.

The Women's Access Work Group produced a definitive set of evaluation research proposals, which included far-ranging sets of questions to be asked of identified organizations, care providers, and individuals. These proposals were aligned along basic issue areas that had been identified by all members meeting together on the 27th of February. On the 28th, detailed discussion and design of research proposals within assigned issue areas were accomplished in breakout sessions by four small subgroups.

This report emphasizes, as did the Women's Access Work Group, the need for evaluation projects focused on the following issue areas:

- Special Needs of Drug Using/Recovering Women
- Training Providers to Serve Women
- Migration
- Intra- and Interagency Policies and Practices
- HIV-Related Support Services for Women
- Continuum of Care
- Special Needs of Adolescent Women
- Program Organizational Development
- Meeting the Needs of Women as Women

To provide readers some of the context from which priority issues were identified and research questions developed, this report also includes a brief summary of participant discussions, most of which took place when the group as a whole met to formulate issue areas. It also

contains, in the appendices, copies of other materials provided to participants, including a summary of sections of the CARE Act pertinent to women and a listing of recommendations made by Federal groups/meetings specific to access for women with AIDS/HIV.

## Summary of Proceedings

**A**t the opening session on Thursday afternoon, February 27, Dr. Moses Pounds explained the purposes of this Work Group and the entire series of access meetings:

- to identify and understand barriers to HIV care
- to develop a framework to deal with access issues specific to particular populations, as well as with those that cut across several populations
- to involve affected populations in defining these issues

Dr. Pounds noted that evaluation issues identified during the meeting should be framed in terms of the CARE Act legislation and whether that legislation has made a difference in improving access to care.

Dr. Eric Goosby, Director of the Division of HIV Services, which oversees the programs funded under Titles I and II of the CARE Act, then briefly summarized the purposes of the CARE legislation and the first year accomplishments of the Title I and Title II programs. Following that, Gloria Weissman led the 15 invited participants in a discussion of the issues that brought them to this table. Research recommendations from other Federally convened meetings on women and AIDS, which had been sent to the participants prior to the Work Group meeting, served as the starting point for this discussion, but it quickly broadened to reflect the diverse experiences and interests of the group. Presented here are some of the major issues--some framed as vignettes--that were raised. While the lively discussion that ensued about women and HIV was far-ranging, an attempt has been made to focus on those issues that related directly to evaluating access to care. Each issue has been placed in one issue area, though it may apply to several. It should be noted that there was a remarkable degree of consensus among the group about what the issues are and what the priorities for evaluation research should be.

## **MAJOR ISSUES IDENTIFIED**

### **SPECIAL NEEDS OF DRUG USING/RECOVERING WOMEN**

- It is imperative to get information, education, and assistance for drug using women into their communities. Identifying and disseminating effective, sensitive strategies for overcoming resistance, denial, and fatalism is a critical need.
- It is also critical to find out how AIDS/HIV is handled in drug treatment programs and to develop strategies for improving the care of HIV infected women in drug treatment. For example, most treatment programs require that clients be drug free; this often includes prescription drugs, such as AZT. For drug treatment programs that do allow medications, many make it solely the client's responsibility to remember dosing schedules and many provide clients only a limited "window of time" each day to get their AZT. Medical and drug treatment providers seldom work together to produce a treatment plan for the client with HIV disease; often they don't "speak the same language."
- We must address the special housing needs of women with HIV who have successfully undergone detoxification and require some sort of residence, ideally drug-free, as they make the transition from detoxification into longer-term recovery.

### **TRAINING OF PROVIDERS TO SERVE WOMEN**

- Licensing and/or funding requirements may be a barrier. For example, in Boston, there are specific requirements as to what kind of person (e.g., level of education, title) has to fill what position at what agency in order for the agency to receive CARE Act funding. Something needs to be done in this regard in order to make practitioners more mobile and the system of care more responsive to the needs of women clients. Physicians assistants, nurse practitioners, and other mid-level health care providers, used in conjunction with trained women from the community itself, may be able to create a more "women friendly" care system, but often there are licensing/funding restrictions that prevent this.
- Another factor is the shortage of obstetricians; many have dropped out because of malpractice suits or fear of them. Many physicians remaining in ob/gyn practice do not want to go into public hospital service; many

others appear not to be interested in learning about or delivering HIV care. Many dentists also are reluctant to receive training in HIV, although the first manifestations of HIV infection often show up in the mouth. Strategies must be developed to address these training issues that create barriers to access.

- Moving a client efficiently and effectively through the social service system requires thorough training and frequent updates.
- HIV-related conditions continue to be misdiagnosed or undiagnosed in women who do seek care; all health care providers coming into contact with women must be better trained in the clinical manifestations of HIV infection. HRSA's AIDS Education and Training Centers (ETCs) need to play a more active role in ensuring that this occurs and that new research findings regarding women and HIV disease are integrated widely and rapidly into clinical practice

## **MIGRATION**

- Migration patterns between Puerto Rico and the mainland may relate to stages of the disease (e.g., migrating out to obtain care, returning to the extended family in advanced stages). For women, particularly, this results in stress on both the family and on the individual with HIV; it may disrupt family support systems and reduce the effectiveness of medical care.
- Immigration and Naturalization Service (INS) regulations regarding HIV status are a barrier to care. Migration over the U.S.-Mexico border occurs; people with HIV frequently come to the U.S. for medical care and go home to die.
- Migration patterns exist within the contiguous states as well. A case diagnosed and reported in one city or state results in funding (under Titles I and II of the CARE Act) for that locale, but the woman with HIV may leave the area soon after diagnosis. Some women may go out of State to get tested because of a desire for anonymity or confidentiality and then return home.

## **INTRA- AND INTERAGENCY POLICIES AND PRACTICES**

- Policies and practices relating to the ways in which service agencies interact pose their own significant barriers to access for women with HIV disease. For

example, as one participant pointed out, there is a special ob/gyn program for women with HIV in Atlanta. However, there is a four to six month waiting time for other clinics in the metropolitan area. Internal and bureaucratic barriers to care exist at service delivery agencies, at the State level, and in the planning councils. Often, there is little or no communication between and among the various providers and levels of providers involved in serving these women.

#### **HIV-RELATED SUPPORT SERVICES FOR WOMEN**

- Support services are critically needed for drug using women with HIV disease, many of whom are members of ethnic minorities, have few financial resources, and lack consistent social and family support systems.
- Many hospices and other care sites for women with advanced HIV disease separate these women from their children. One participant reported, for example, that in Los Angeles there are 12 hospices, but that these seldom take women with children. Women needing this kind of care often are faced both with finding someone to whom they can entrust their children and with finding ways to maintain contact with the children during this very difficult period. It is important to develop and evaluate: residential programs that accommodate both women and children; and programs that bring trained personnel into a woman's home to care for her and help her care for her children as long as possible.
- Women with HIV disease need training/support in a number of areas. One of the areas in which many need help is how to tell their children they have HIV/AIDS. Also, they often need to be educated about HIV treatment options and how to use the treatment system to their best advantage.
- Religious leaders and their congregations often can't be used to educate families and mobilize support for HIV infected women; some view these women as sinners. Religious leaders, including lay clergy, need to be educated in order to make this valuable community institution a more accessible resource for women with HIV.



## CONTINUUM OF CARE

- In talking about continuum of care issues, it is important to recognize that women may require additional services not needed by other populations with HIV. One participant noted that in Boston, the full service programs were not adequate for women, who "fell out" of the continuum faster than male clients. Most vendors had built their "continuum" of service to provide care for the upper class gay white men and had not designed programs (such as home care) for women.
- It is important to examine where and how HIV positive women enter or potentially enter the care system. For example, in New York City, there is a three to six month wait for gynecological care in the public hospitals. As a result, 80 percent of the women who come into the hospital come through the emergency room. This means that for many poor, potentially HIV infected women, there is no basis on which to build access to continuing care.
- It would be worthwhile to examine the degree to which the CARE Act could or should be used to connect women with HIV infection with ob/gyn care in a routine/monitoring capacity. To do this, we should consider developing and requiring standards of care, i.e., routine pap smears, etc.
- There is a need for decent housing and supervised living arrangements for HIV patients. At some time, almost every PWA will need this. There are other precedents, e.g., senior citizens buildings. In Los Angeles, two houses exist for women with HIV who are recovering from substance abuse. Fifty-five women are in residence; 49 of them have no mothers to take care of their children. The funding agency for this housing requires that a resident woman must participate at least 20 hours in drug treatment per week. If they are too ill to participate at this level, they are not permitted to stay in the housing. Turnaround housing is needed for these women in order to bridge the gap between residential treatment facilities and hospice care.

## SPECIAL NEEDS OF ADOLESCENT WOMEN

- Many women adolescents, particularly those at highest risk for HIV, have no access to care because they have no insurance. There is a tremendous need in this area and

it is steadily growing. The care that does exist for women of this age group may frequently be located in family planning clinics; however, many adolescents are not interested in these services. As a generally healthy population, adolescents have not had to deal with getting health services and don't have the skills, experience, or patience to negotiate complicated health and social service systems. In fact, many have severe, long-standing medical problems, apart from HIV, that have never been attended to. By 1994, Medicaid is supposed to cover all adolescents up to the age of 18, but we are faced with enormous access issues now.

#### **PROGRAM ORGANIZATIONAL DEVELOPMENT**

- In some localities, CARE Act funding has gone to hospitals and larger organizations, while community groups have had difficulty competing successfully for funding. On the other hand, community-based agencies providing HIV care are not necessarily "women friendly." It is important both to find ways of evaluating their programs in terms of how well they accommodate women's needs and to develop strategies for helping them to do this better. It is also important to devise strategies for building HIV care capacity in agencies that have a proven track record in providing other services to women, particularly those with poor access to care.
- It is essential to design evaluation frameworks that are staged/tiered. If evaluation protocols similar to those used in the past are employed, the accomplishments of small, new organizations with particular empathy for and effectiveness in dealing with women clients may not be recognized. We must find ways of measuring provider sensitivity, client satisfaction, quality of staff, and quality of care. Client retention is as important as client enrollment.

#### **MEETING THE NEEDS OF WOMEN AS WOMEN**

- Many women who seek care or who need care are not reached by a health system oriented to seeing primarily or solely in the context of their reproductive functions. While it is important, where appropriate, to look at women's care in a family context, many women with HIV do not have children or live in a traditional, nuclear family structure. The full range of medical and support services should be available to all women with HIV.

Too often, women with HIV are linked to care through their children or through reproductive health agencies. In addition, many women with HIV fall outside of the usual "risk categories." Access to appropriate care may be particularly problematic for these women because they are often overlooked by funding sources.

- Evaluation is needed to assess whether planning councils are taking effective steps to fulfill their responsibility for dealing with women's issues.

After two hours of discussion on the first day, participants examined the many issues raised, picked the above as main topics, and assigned each of the four breakout clusters an issue or issues, as noted below, for the next day's working session. Each group was charged with developing a design for what it considered the priority evaluation study(ies) in each of its issue areas. A facilitator and a reporter was to be chosen by each group; one HRSA staff person was assigned to each group as a recorder.

#### **Group A Participants:**

- Dorothy Bailey (recorder)
- Vivian Brown (facilitator, reporter)
- Annette Johnson
- Linda Smith

*To examine: Special Needs of Drug Using/Recovering Women; Training Providers to Serve Women*

#### **Group B Participants:**

- Judith Cohen
- Dazon Dixon (facilitator)
- Missy LeClair
- Virginia McCoy (reporter)
- Martha McKinney (recorder)
- Verna Robertson

*To examine: Migration; Intra- and Interagency Policies and Practices; and HIV Related Support Services for Women*

#### **Group C Participants:**

- Eda Valero-Figueira (recorder)
- Diane Lewis
- Jeannine Salone
- P. Clay Stevens (facilitator, reporter)

*To examine: Continuum of Care*

### Group D Participants:

- Hortensia Amaro
- Andrea Carr
- Christina Lewis
- Katherine Marconi (recorder)
- Dooley Worth (facilitator, reporter)

*To examine: Special Needs of Adolescent Women; Program Organizational Development; and Meeting the Needs of Women as Women.*

After intensive group discussion and deliberations spanning 7-1/2 hours, the breakout groups reconvened to present their proposals to the assembled group. Approximately 30 invitees from private and public sector organizations involved in HIV issues attended this closing session to hear the group's deliberations.

A number of recommendations for HRSA and BHRD were generic and had implications for policy, program development, and technical assistance; consequently, they are presented apart from the research proposals. These are listed first, in order to give some additional insight into the deliberations of the groups. These general recommendations are followed by the detailed research proposals developed by each breakout group.

### **GENERAL RECOMMENDATIONS**

1. Federal, State, and local governments should set aside funds for HIV services for women that are not restricted by categories or labeling (mothers, drug users, etc.)
2. HRSA should establish a national 800 number for physicians diagnosing and treating women to call in order to receive/exchange information. The line should be staffed by physicians, physician assistants (PAs), and nurse practitioners (NPs) knowledgeable about HIV in women.
3. HRSA should videotape some of the client focus groups assembled for its evaluation projects and disseminate these tapes as educational tools to providers, legislators, etc.
4. HRSA staff must actively support/enforce efforts by the CARE Act Title I and Title II grantees to increase access to, improve, expand, and enhance services specifically tailored to the needs of women with HIV disease. HRSA staff (including legal staff) must be educated about the

importance of meeting the legislative requirements around this issue. Funding/refunding decisions should take into account whether grantees improved the delivery of services for women with HIV.

5. All care providers funded by HRSA should be actively encouraged to participate in AmFAR's observational data base and submit information regarding female symptomatology, including onset, duration, and intrac-tability.
6. Care providers funded by HRSA should be actively assisted to establish and maintain linkages with both publicly and privately funded research programs in HIV.
7. In conducting evaluation studies and looking for poten-tial sources of data and methodologies, HRSA should take advantage of other resources that it funds, e.g., the automated case management systems already in place in several Title I cities.
8. There should be more active linkages between CARE Act programs, CDC's HIV programs, and other Feder-ally funded HIV programs. These need to be established on the Federal, State, and local levels.
9. Additional research is needed in the following areas and should be supported by HRSA, Agency for Health Care Policy and Research (AHCPR), Substance Abuse and Mental Health Services Agency (SAMHSA), and other agencies involved in services research and evaluation:
  - How do women's roles as heads of household / providers/care givers affect their own care?
  - How does sexual identity and sexual practices affect a woman's choice of provider, kinds of care, types of services, access to services, etc.?
  - How best can women's reproductive choices and plans be addressed vis- a-vis their HIV status?
10. Additional research is needed in the following areas and should be supported by the Centers for Disease Control (CDC) and the National Institutes of Health (NIH):
  - How do women's roles as providers/care givers affect their own risk for HIV infection?
  - How does female bisexual behavior affect women's risk for HIV infection?

- How does male bisexual behavior affect women's risk for HIV infection?
  - How does sex between women affect their risk for HIV infection? How does lesbian identity affect risk for HIV infection?
  - How does drug use (single or poly; self or partner's) affect women's risk for, and ability to avoid, HIV infection?
  - How does access to/attitudes toward/use of condoms/dental dams affect women's risk for HIV infection?
11. The Food and Drug Administration (FDA) and NIH should have some special requirements about women for both their traditional clinical trials and parallel track studies. A sufficient number of women must be enrolled for adequate evaluation of outcome (statistical conclusion validity). Clinical trials should include funding for transportation, childcare, out of town lodging (for both client and companion), etc. The Investigation/Human Subjects Review Boards must see that informed consent is provided to women regarding reproductive choices and birth control methods and differently challenged individuals. There also should be some women-specific research in these areas.

## **Evaluation Research Proposals**

### ***Research Proposals, Group A***

#### **ISSUE AREA: SPECIAL NEEDS OF DRUG USING/RECOVERING WOMEN**

In looking at the broad question of how well the needs of drug using/recovering women with HIV disease are being met and what the contribution of CARE Act funding has been, Group A identified four priority areas for evaluation. They proposed the following studies:

#### **I. EVALUATION OF HOW WELL DRUG TREATMENT PROGRAMS ARE MEETING THE NEEDS OF WOMEN WITH HIV**

##### **A. Type of Study/Methodology**

- Community-based
- Multi-site
- Title I cities with active outreach programs to women drug users not currently in treatment
- Semi-structured interviews

##### **B. Participants**

- Outreach workers
- Drug treatment clients
- Ex-clients
- Potential clients (reached by outreach workers, but not in treatment yet)
- Other human service agencies, e.g., health, social services, mental health
- Drug treatment programs

##### **C. Questions to be Addressed**

1. Does the program have an HIV treatment component?
  - Is HIV/AIDS an integral part of the drug treatment program or is it an add-on?

- Is the whole staff trained and periodically updated on HIV?
  - Is HIV testing provided at the site plus pre- and post-test counseling available on site?
  - How is counseling done? Are there written protocols used? How are counselors trained?
  - Is there an HIV / AIDS education program and of what does it consist? At what stage in treatment is it delivered?
  - Is there HIV education and support for clients' families? How does the program define family?
  - Is there ongoing staff support and supervision around HIV issues?
2. Are programs' policies sensitive to special needs of HIV women?
- Is there priority admission for HIV positive women?
  - Can intake for drug treatment be done in other centers, e.g. AIDS programs, hospital ERs, family planning, hospital AIDS clinics, community and migrant health centers?
  - Do you have outreach workers, and are they from the communities you serve?
  - What are your admission policies and procedures? Are there any that might exclude HIV positive women; e.g., do you require that clients take no medications?
3. Are there coordination and linkages with other programs in the community to meet the needs of HIV positive women?
- Is there housing available for the women after treatment?
  - Is there attention paid to the special legal issues HIV positive women face? Are there linkages to legal services (living adoption, confidentiality, power of attorney, living wills, special entitlements such as Social Security or other financial supports)?
  - Are there linkages to primary health care, offsite or onsite? Are ob/gyn and dental services included? Is attention paid to providing a continuum of care? What services are provided onsite? For offsite services, what is the nature of the linkages?



- Is there family-centered hospice care? (Family includes the children, parents and partners of HIV women).
- Is there a linkage to home-based care?
- Are there linkages to programs that will provide the HIV positive woman with support/counseling that can help her tell her children and other family members about her HIV status?

## **II. EVALUATION OF THE IMPACT OF THE CARE ACT ON THE PROVISION OF SERVICES TO DRUG USING/RECOVERING WOMEN WITH HIV**

### **A. Type of Study/Methodology**

- 1-year cross-section followed by a 3 to 5 year prospective study
- Cities with high prevalence but not yet receiving Title I funds, such as Detroit, Tampa, Seattle, matched geographically/demographically with similar cities already receiving Title I funds
- Semi-structured interviews

### **B. Participants**

- Planning Councils
- Drug treatment agencies (their clients and ex- clients)
- Outreach programs serving women drug users (their clients and ex- clients)

### **C. Questions to be Addressed**

1. Since the advent of the CARE Act, are there more places to refer drug using/recovering women with HIV disease for services?
2. Have there been increases in the number of drug using women referred from drug treatment to other services and from community settings to other services, such as mental health, health, and social services?
3. Has there been follow-up of these referrals? What was the result of the referrals?
4. Are there more home-based care services?

5. Is there other funding coming into these programs from Title II sources?
6. What are the plans to continue services (from year to year and post CARE Act funding).
7. What priority level has been given to services for drug using and former drug using women at city and State level (Titles I and II). Is priority given only to services for pregnant women?
8. Are there improved linkages between drug treatment and primary care services. Describe, from a client perspective.
9. How do drug using/recovering women perceive accessibility of primary care? What specific steps have been taken to remove barriers? (e.g., bundling of services and one-site services; having outreach workers or case managers walk women through services).

### **III. HOW ARE THE NEEDS OF DRUG USING/ RECOVERING WOMEN WITH HIV BEING ADDRESSED IN THE PLANNING PROCESS FOR ALLOCATING CARE ACT FUNDS?**

#### **A. Type of Study**

- Process evaluation Title I cities: New York, Los Angeles, and Philadelphia; 3 to 4 states such as New York, California, Pennsylvania, and Texas

#### **B. Methodology**

1. Interview key informants both inside and outside planning councils and consortia
2. Review documents: minutes of planning council and consortia meetings; minutes of subcommittee meetings; grant applications; council and consortia membership rosters; public hearing minutes of States; RFPs for Title I and II contracts and subcontracts; plans for evaluations; intergovernmental agreements; needs assessments
3. Observe council and consortia meetings

#### **C. Questions to be Asked**

1. Are the drug using or recovering women with HIV actively involved in the planning process at all stages and are they involved in key roles within the planning process?

2. When and how in the planning process are drug using/recovering women involved?
3. Are agencies sensitive to and knowledgeable about issues facing drug using and recovering women with HIV actively involved in the planning process at all stages?
4. Were the priorities established by the planning process implemented in priority order?
5. Are there women and agencies serving women involved in the review process for funding?
6. Have small community-based agencies received CARE Act funding to serve women?
7. Does the city or State provide technical assistance to the women-focused, small community-based organizations in their application process? Is such technical assistance provided on an ongoing basis?
8. Do cities/States provide capacity building?
9. Is there a priority given to addressing interagency barriers to the provision of a continuum of care for drug using/recovering women with HIV.
10. Are agencies/programs that have been providing outreach/prevention services to drug using/recovering women included as part of the planning and priority setting process in order to ensure a true continuum of care?
11. Are cities/States modifying licensing/waivers/Medicaid and public assistance policies to facilitate delivery of Ryan White services by agencies/provider types sensitive to the needs of drug using/recovering women? (For example, outreach workers may be uniquely qualified to do case management for this population, but may not be able to meet case management licensing requirements.)

#### **IV. STUDY OF DRUG DETOXIFICATION PROGRAMS AND THEIR ROLE IN THE TREATMENT OF WOMEN WITH HIV**

##### **A. Type of Study/Methodology**

- Sample of selected Title I cities
- Sample of medical and social model detoxification programs
- Interview clients, ex-clients, staff of detoxification programs and outreach workers
- Have trained drug treatment personnel do observations

##### **B. Questions to be Asked**

1. What is the length of treatment (average, maximum)?
2. What are the admission criteria? Are pregnant women accepted? Does the program take both men and women? Is HIV status ascertained? Are HIV positive clients accepted? Are HIV positive clients given priority? Are certain residential areas served? Is the program limited to individuals using certain drugs (e.g., heroin, cocaine, alcohol)? How are applicants screened? What are the admission procedures?
3. Is there centralized intake or decentralized points of entry? What are the intake procedures?
4. How many beds does the program have in all? What are the funding sources per bed - public, private, voluntary?
5. How well are HIV positive women clients linked to needed services after detoxification; how are they linked, and does linkage include primary care?
6. Is HIV testing and counseling and education provided routinely? What are the counseling protocols? Is staff trained on HIV issues? What is the nature of the training?
7. What other health/support services are provided during and as part of the detoxification period? How many clients go on to longer term drug treatment? Are there special incentives/policies that encourage this for HIV positive women?

8. Is detoxification part of a larger drug treatment program? If not, are there outreach workers or case managers who can link clients with the next level of service? How is this done?
9. What kinds of primary care services are provided by whom and where?

## **ISSUE AREA: TRAINING PROVIDERS TO SERVE WOMEN**

Group A identified two pressing evaluation needs in the area of professional training: to study how providers working with HIV positive women are being trained; and to determine how existing training resources are being and can be utilized to help providers improve access to care for women with HIV disease. Two evaluation studies were outlined.

### **I. EVALUATION OF HOW AND HOW WELL PROVIDERS WORKING WITH HIV POSITIVE WOMEN ARE TRAINED**

#### **A. Type of Study**

- Sample of Title I cities
- Sample of Title II States with consortia

#### **B. Methodology**

Interviews of:

-key informants (e.g., planning council members, consortia members, State AIDS training directors)

-clients

-staff (about training needs)

- Examine documents and training manuals, with particular reference to women's needs
- Observe staff at work; observe staff being trained
- Examine provider and grantee budgets regarding provision of training for programs working with women (note, however, that many CBOs may trade/barter training with other organizations; training may not, therefore, appear as a budget item).
- Examine a cross section of training programs in these areas: HIV services; community/home based care; drug treatment; primary care. Include those developed by the Federal government (i.e., ETCs)

### C. Questions

1. What kinds of HIV training resources (curricula and trainers) are currently available to what kinds of providers?
2. What are the barriers to offering or receiving training (cost, time, location)?
3. What are the current requirements and incentives (as well as disincentives) for training? What requirements and incentives could increase participation by providers?
4. Who sets the training standards for staff? Who develops guidelines and protocols?
5. From the perspectives of both clients and staff, what are the most important training needs for staff dealing with women?
6. Who is most effective in delivering the training? Who is doing the training? Are HIV positive women being used as trainers?
7. Does the training include work on gender issues and sexism? What are the barriers to including this?
8. Are there educational opportunities and career ladders for community outreach workers, buddies, home care workers, and volunteers? How are these individuals trained?
9. Are there mechanisms (e.g., cross training among disciplines and job rotation) to manage burnout and ensure staff growth?
10. Are licensing/certification requirements a barrier to staff growth? Are they potential barriers or facilitators to enhanced care for women. Are women who are HIV positive included in the groups that are being certified?
11. Does the Planning Council set training as a priority and monitor/evaluate training among providers funded under Title I? Do consortia fund and/or provide training?
12. Are training and technical assistance being given in an ongoing way to community based organizations (including those funded and not funded through the CARE Act) to facilitate capacity building?

13. Is training on women's issues being provided by organizations that are demonstrably sensitive to women's needs? Is the training designed and delivered by women?
14. Is there a needs assessment done before training is given (from both program and staff perspective) for both in-house and external training?

## **II. EVALUATION OF EXISTING TRAINING CENTERS AND RESOURCE FOR UTILIZATION AND SUITABILITY**

### **A. Type of Study/Methodology**

- Interview funding agencies (e.g., HRSA, SAMHSA, National Institute on Drug Abuse, National Institute of Mental Health)
- Interview directors and administrators of major training centers (ETCs, NIMH centers, NIDA's Center for HIV and Substance Abuse, Visiting Nurse Association)
- Interview trainers and trainees  
Examine:
  - curricula
  - evaluations
  - outcome assessments and followup (who conducted)

### **B. Questions to be Asked**

1. Who is being trained through these centers?  
Numbers and discipline
  - Gender
  - Professional roles
2. Who is doing the training?
  - Numbers and discipline
  - Gender
  - Professional roles
  - What kind of experience do the trainers have with HIV positive women?
3. When were curricula developed, by whom, for what purpose? How often are they updated? Are they being used now? By whom? For what purpose?
4. What is the process of planning and implementing the training (at the level of the centers)?





## **Evaluation Research Proposals**

### ***Research Proposals, Group B***

#### **ISSUE AREA: MIGRATION**

Group B felt that before evaluating the impact of migration upon HIV positive women's access to care, it was critical to perform indepth research on the factors motivating these women to move. Accordingly, they proposed the following study as a first priority in this area:

#### **I. STUDY OF FACTORS THAT AFFECT HIV POSITIVE WOMEN'S DECISIONS TO MOVE**

##### **A. Major Issues**

1. What are the major factors affecting migration among HIV positive women? How do these factors differ for women of different ages, incomes, educational levels, etc.
2. To what degree does migration occur in order to access medical and support services?
3. If medical and support services are an important factor, to what extent are they (or can they be) funded by the CARE Act?
4. What are the costs and benefits of migration--if any? What are women's perceptions of medical and social services?
5. How does employment status and insurance coverage relate to migration?

##### **B. Type of Study/Methodology**

- Multi-site pilot study in 3-6 cities where there are migration streams.
- Sample should include:
  - Cities with Title I and cities with Title II funding
  - Rural and urban cities
  - Cities affected by "airbridge" migration (Puerto Rico to states and vice versa)

- Cities that are major sites of illegal immigration

- Consider 4 kinds of migration: state-to-state; within state; Puerto Rico to/from states; across the U.S. border.
- Random sample of HIV positive women from prenatal clinics, STD clinics, private clinics--the range of testing and early diagnostic and treatment sites available to women.
- Semi-structured interviews, standardized across sites

**C. Questions to be Asked**

1. What are the most important factors in HIV positive women's decisions to move?
2. What is their knowledge and awareness of medical and support services in both cities?
3. What do their support systems, formal and informal, look like?
4. Are there other needs, unrelated to HIV, that they feel have priority?
5. What resources (employment, insurance, etc.) do they have?
6. What are their roles as caretakers?
7. What are their roles within their family (traditional or non-traditional) structures?
8. What are their perceived needs for services?

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**ISSUE AREA: INTRA- AND INTERAGENCY  
POLICIES AND PRACTICES**

Group B identified as the most critical need a study that would: identify, from several different perspectives, the intra- and interagency policies presenting barriers to access for women with HIV; and evaluate some strategies for overcoming these barriers. They outlined the following study design:

**I. WHAT ARE THE INTRA- AND INTERAGENCY  
POLICIES AND PRACTICES THAT PRESENT BARRIERS TO  
ACCESS FOR WOMEN WITH HIV?****A. Type of Study/Methodology**

- Small evaluation grants to a few communities (perhaps to women's groups)
- Assemble focus groups of service providers and clients to identify the various intra- and interagency policies/practices that present financial, logistical, cultural, etc. barriers to women's procurement of HIV-related services.
- Conduct a survey of service providers, clients, and Title I planning council members, asking them to rank the access barriers in terms of their importance.
- Get recommendations from service providers and clients on how to solve the most pressing problems. Develop and implement appropriate interventions.

**B. Define access in terms of:**

- Financial barriers
- Logistical barriers (e.g., transportation, child care)
- Time barriers (e.g., hours/days when services are offered)
- Cultural barriers
- Adequacy of social support
- Environment (whether women feel comfortable in the setting)
- Provider-client relations (how women are treated)

**ISSUE AREA: HIV-RELATED SUPPORT SERVICES FOR WOMEN**

In order to evaluate the impact of the CARE Act on the provision of support systems for women with HIV, Group B felt that the following three studies were the highest priority. They also felt that all of these studies lent themselves well to the same type of study design.

**I. EVALUATION OF THE EXTENT TO WHICH HIV PLANNING COUNCILS AND HIV CARE CONSORTIA ARE PROVIDING SPECIFIC FUNDS/PROGRAMS THAT ADDRESS THE SUPPORT NEEDS OF HIV POSITIVE WOMEN**

**II. EVALUATION OF THE EXTENT TO WHICH PREVENTION AND (SUPPORTIVE) EDUCATION ARE BEING INCORPORATED INTO THE ENTIRE CONTINUUM OF CARE FOR HIV POSITIVE WOMEN**

**III. WHAT BRIDGE SERVICES ARE AVAILABLE TO WOMEN WITH HIV/AIDS? (BRIDGE SERVICES ARE DEFINED AS SERVICES THAT LINK ONE TYPE OF SERVICE TO ANOTHER (E.G., TEMPORARY GUARDIANSHIP, EMERGENCY CHILD CARE UPON HOSPITALIZATION))**

**A. Type(s) of Study**

- Survey all HIV health services planning councils and HIV care consortia regarding these questions.

Or

- Two-step approach: (1) provide small grants to selected planning councils for a self-assessment that addresses these research questions; and (2) have an external evaluation panel (composed of people living with AIDS) visit the cities to examine the same questions, validate self-assessment findings, and explore additional (or related) issues.

## **Evaluation Research Proposals**

### ***Research Proposals, Group C***

#### **ISSUE AREA: CONTINUUM OF CARE**

Group C proposed one study that would define an ideal continuum of care for women with HIV and determine whether it exists in eligible metropolitan areas (EMAs) funded under Title I of the CARE Act and to what extent CARE Act funding has made it possible. A second study identified by the group as a priority would focus on whether the presence of each service in the continuum correlates with client satisfaction and use of the system as a whole.

#### **I. STUDY OF WHETHER A CONTINUUM OF CARE SPECIFIC TO THE NEEDS OF WOMEN EXISTS IN A PARTICULAR STATE OR TITLE I CITY**

##### **A. Type of Study/Methodology**

- Survey to be administered among hospitals, AIDS service organizations, community-based organizations, walk-in clinics, and acute care sites
- Uses a "spread sheet" with two axes, to be based on an "ideal continuum of care"
- This "ideal continuum" to be based on existing research and validated by both providers and clients
- Weighted values to be assigned to each item on the chart
- Could be done as separate evaluation study, as part of HRSA's ongoing program monitoring activities (including site visits), or as part of the application process

##### **B. Composition of the survey chart**

1. On vertical axis, list of services, to include:
  - Establishment of responsibility unit
    - Assigning coordination of each individual's care to a medical person (MD, NP, PA), a social work person

(social worker, counselor, case worker, volunteer), and a community-based person

- Outreach/case finding
  - Including primary prevention
- Basic intake assessment
  - Assessment of medical, social services, support system
  - Assessment of short-term needs and long-term needs
  - Intake exam and establishment of follow-up schedule
- Secondary prevention
  - Education about services available, health maintenance measures
  - Behavioral change support
- Long term care coordination
  - Social worker/case manager
- Primary care
  - Ob/gyn care
  - Infectious disease and HIV
  - Pediatric care
  - Family practice
  - Links to research protocols (e.g., clinical trials)
  - Early intervention (e.g., prophylactic medications)
  - Symptomatic treatment
  - Tuberculosis
    - Screening
    - Support Services
    - Observation for MDR TB patients taking medications
- Case management, including case management for asymptomatic patients
- Acute care, including inpatient and emergency room
- Long-term care
  - Hospice
  - Nursing Home
  - Respite care

- Home care
  - VNA treatment
  - Infusion treatment
  - Homemaker
  - Home health care
- Therapies
  - Occupational
  - Physical
  - Alternative (herbs, acupuncture, etc.)
- Other services
  - Meals
  - Housing
  - Buddies
  - Transportation
  - Childcare
  - Family care
  - Car seats/strollers
  - Pastoral care
- Entitlement programs
  - SSI
  - SSDI
  - Medicaid
  - AFDC
  - WIC
  - General Assistance/Relief
- Grief and bereavement counseling
- Funeral arrangements/expenses
- Legal services
- Insurance (including COBRA)
- Provider education and needs
  - Basic education
    - Natural history of HIV in women
    - Access issues for women
    - Periodic updates on these

- Special education
    - Treatment drugs (effects and side effects)
    - Dosages
    - Common complaints vs. symptoms of HIV
    - Birth control vs. safer sex
    - Reproductive choices
    - Psychosocial vs. neuropsychological vs. side effects of HIV treatment
    - Entitlement regulations and terminology
  - Psychosocial services for providers
    - Mandatory
    - Part of job description
    - Facilitated team meetings
    - Attitude adjustment
      - Formal and informal opportunities/ mechanisms for addressing sexism, racism, ageism, homophobia, and addictophobia
      - Formal and informal opportunities/ mechanisms for addressing issues of authority and interpersonal and organizational dynamics
    - Administrator/Board personnel policy
      - Hiring
      - Evaluation
      - Firing
    - Computerized entry/follow-up system
      - Including options for personalized system vs. service system
2. Horizontal axis to include items related to administration of, access to, and quality of items on vertical axis

#### **Administration**

- Service in place (Y/N)
  - Month/year initiated
- Client participation in service design (Y/N)
- Numbers of clients receiving service



- HIV+
- AIDS
- Waiting list
  - Y/N
  - Number of clients
- Agency chief has received HIV / AIDS training (Y/N)
- Gender of agency chief (M/F)
- Agency's total budget
- Agency's total HIV / AIDS budget
- Agency's CARE Act budget
  - Title I
  - Title II
- Board/administrative policy in place re: responsible team needs (Y/N)
- Participate in AMFAR's Observational Data Base (Y/N)
- Participate in local computerized service base (Y/N)
- Ongoing client advisory board
  - Women representatives
  - Women representing a variety of ethnic/racial groups
  - Lesbian representatives
- Staff
  - Women living with HIV / AIDS
  - Professional women
  - Women from diverse ethnic / racial backgrounds
  - Lesbians
- Policy regarding HIV disease among staff
- Linkages with CDC, NIDA, Office for Treatment Improvement (OTI), and other outreach/prevention efforts

**Access**

- Childcare
  - At agency
  - In home
- Transportation
  - Supplied
  - Reimbursed/paid
  - Assisted (car seats, volunteer)
- Family care (same as childcare for other family members)
- Languages spoken (including sign)
- Languages and literacy levels of brochures/intake forms
- Translators available
- Linkage system to other services/agencies in place
- Meals provided during multi-hour service/waiting time
- Handicapped accessible (ADA)
- Charge for services (Y/N)
- Sliding Fee Scale
- Entitlement application required (Y/N)
- Attitude adjustment training in place for staff(Y/N)
  - If yes, specify

**Quality**

- Mandatory staff support activity in place (including primary/secondary prevention and behavioral change support for staff) (Y/N)
- Access to updates on HIV care for staff
- Provider education (see list)
- Participation in community-based research

## II. EVALUATION OF HOW THE PRESENCE OF EACH SERVICE CORRELATES WITH CLIENT SATISFACTION/USE

### A. Type of Study/Methodology

- Personal interviews with clients
- Sample drawn from PWA organizations, AIDS service organizations, community-based organizations, hospitals, walk-in clinics, and acute care sites
- Must include women currently in the system, women not in the system, and women who have dropped out of the system
- Use open-ended questions as a preliminary step
- Pursue comments/details
- Submit list of services (from continuum of care spread sheet)
  - Yes, use
  - Yes, would like
  - No, don't need
  - Does family member need service
- Include range of client/service area demographics

### B. Questions to be asked

- What services do you now receive?
  - From whom?
  - For how long?
  - Do you think they are satisfactory?
  - Problems?
  - Good points?
  - Attitudes of staff members towards you and others?
- Client-identified service gaps
  - List unmet needs?
  - Are you aware of these services being provided in \_\_\_\_\_ (name of agency)?
  - Why are you not using them?
  - If you have stopped/dropped out, why/what circumstances?
- Client's general wish list regarding her HIV care
- Client general hate list regarding her HIV care

## **Evaluation Research Proposals**

### ***Research Proposals, Group D***

#### **ISSUE AREA: SPECIAL NEEDS OF ADOLESCENT WOMEN**

In order to evaluate how the CARE Act is helping to meet the special needs of adolescent women with HIV, Group D felt that it was critical both to look at programs and how they are responding in terms of services and also to examine in-depth what the most important barriers to care are from the point of view of the adolescents themselves. In fact, the latter was seen as a prerequisite to the former. Three studies were identified as priorities:

#### **I. EVALUATION OF HOW TITLE I PROGRAMS ARE RESPONDING TO NEEDS OF ADOLESCENT WOMEN**

##### **A. Type of Study/Methodology**

- Written survey of all Title I Programs and their funded providers
- Survey to be developed by HRSA and a working group of service providers with track record in adolescent care, using data gathered from adolescents themselves through focus groups or interviews
- Part of survey directed at Title I planning councils, the other at providers

##### **B. Planning Council-Focused Questions**

1. Were needs of adolescent women addressed in the planning process? How?
2. How were the special issues of HIV care for adolescent women represented? Was there participation on the Council by adolescents or by providers working with adolescents? In subcommittees or workgroups? What was the nature of the participation? Were there public hearings or other meetings on these issues?

##### **C. Provider-Focused Questions:**

1. What percentage of your clients are adolescent women?

2. Do you have programs specifically tailored to adolescents or only for adolescents?
3. Are these coed or just for young women?
4. Do you provide family planning and ob/gyn services to adolescents? Do you provide other medical services to adolescents?
5. Are there drug treatment programs or designated drug treatment slots for adolescent women?
6. Are the adolescents in your program covered by private insurance? Other reimbursement mechanisms?
7. What are staff capabilities, in terms of language and ethnic background?
8. What are the eligibility criteria for entering your program? Do any of these intentionally or unintentionally restrict access by adolescents?
9. What mental health and other support services are being provided for adolescent women?
10. What kind of staff training is offered about adolescents and their special needs? Who receives it? Who provides it?

## **II. QUALITATIVE STUDY OF HIV POSITIVE ADOLESCENTS' VIEWS OF CARE**

### **A. Type of Study/Methodology**

- Focus groups of adolescent women with HIV
- Conducted by consultant hired by HRSA
- Sampling from both higher incidence and, if possible, lower incidence areas
- Stratify by ethnicity, if possible
- Include adolescents of different ages and different socioeconomic status

### **B. Areas of Investigation**

1. Adolescents' views of what motivates them to seek health and psychosocial services
2. Their knowledge of what services exist
3. What they find helpful and what they do not find helpful when they seek/receive care
4. What attracts them to particular services/types of services

5. What keeps them from particular services/types of services
6. What drives them away
7. What their history of care has been
8. How they have been treated by professionals

### **III. SURVEY STUDY OF HIV POSITIVE ADOLESCENTS' VIEWS OF CARE**

#### **A. Type of Study/Methodology**

- Survey of adolescent women in high risk and low risk areas. (Separate survey of adolescents in high risk areas may not be justified at present time.)
- Possibility of adding on to existing survey or obtaining data from survey of other agencies in high risk areas should be considered.
- Sample of cities should include a variety of regions, ethnic minority populations; special effort should be made to reach Asian and other more "hidden" populations.
- Sampling frame: adolescent women receiving medical care; other adolescent women (high risk and not high risk).
- Put together as one sample, not by city.

#### **B. Areas of Investigation**

1. Do eligible adolescents know about different types of services?
2. What are the barriers to accessing and obtaining services, e.g., linguistic, individual, social, economic, legal, institutional?
3. Are there special concerns about confidentiality?
4. What is their history of using services?

## **ISSUE AREA: PROGRAM ORGANIZATIONAL DEVELOPMENT**

Group D identified as the most pressing need in this area a study that would examine how CARE Act funding has contributed to capacity building in agencies serving--or potentially serving--women with HIV disease. It proposed the following study design:

### **I. EVALUATION OF THE IMPACT OF THE CARE ACT ON CAPACITY BUILDING IN AGENCIES THAT HAVE PROGRAMS FOR WOMEN WITH HIV**

#### **A. Type of Study/Methodology**

- Telephone or in-person interviews of sample of agencies that have specific programs for women with HIV
- Include agencies that did and did not apply for CARE Act funding Sample of communities
- Semi-structured interviews by consultants
- Interview: service providers; Executive Director; members of Board of Directors
- Comparison group of agencies that have female clients, but no specific HIV-related programs for them

#### **B. Questions**

1. Prior to the CARE Act, did the agency offer programs to women with HIV? What were the nature of these programs? What kinds of clients were served?
2. Did the agency know about CARE Act funding and did it apply? If not, why not?
3. What capacity building services related to the provision of HIV services are needed by the agency? (These might include help in recruiting appropriate staff, provision of training, development of HIV-related services, development of expertise or skills to attract funding for other HIV-related services.
4. Were any CARE Act (Title I or Title II) funds used for capacity building services? How was capacity building defined? Was funding for/provision of these services limited to certain types/sizes of agencies? What kinds of capacity building services were funded/provided?

5. What impact did these capacity building services have on the agency's participation in the local HIV planning process and integration into the referral system?
6. What services does the agency want to add in order to do the kind of program for women it envisions? Has CARE Act funding helped the agency to fill the gap(s)?
7. What kinds of problems resulted from the capacity building?
8. How did the cycle of funding impact capacity building?
9. Did the any CARE Act funding received help cover core administrative costs?
10. Did any CARE Act funding received enable the agency to evaluate outcomes by doing follow-up and program and process evaluation? If you could know something about your own program that you don't know, what would it be? What are the obstacles to evaluating your own program?

### **ISSUE AREA: MEETING THE NEEDS OF WOMEN AS WOMEN**

Group D felt that there was a pressing need to evaluate whether and how the needs of women with HIV as women--not as mothers, partners, drug users, etc--are being identified and addressed by CARE Act funding. They proposed three different studies to accomplish this evaluation goal.

#### **I. EVALUATION OF WHAT PROGRAMS FUNDED BY THE CARE ACT ARE DOING TO MEET THE NEEDS OF WOMEN AS WOMEN**

##### **A. Type of Study/Methodology**

- Survey of programs in selected Title I cities
- Could be added on to the evaluation of the continuum of care for women (See Group C)

##### **B. Questions**

- Are there eligibility criteria that systematically exclude women or certain women from services?



- What is the range of services provided to HIV positive women? Are they focused on women's reproductive roles?
- Are all the services offered designed to accommodate women's needs, or is this true only of those services offered to women alone?
- Is it the norm for the women to come to the providers or for the providers to go to the women?
- Are services available for clients on Medicaid, General Assistance, private insurance, or without any insurance? How does service availability differ depending on payment source?
- Is onsite drug treatment or referral to drug treatment available for women?
- Are legal services (disability, custody, housing, social security) provided to women?
- Are child care, respite care, transportation, counseling, housing, and support services provided?
- What procedures are in place to retain women in services? To maintain or reestablish contact with those who drop out?
- What kind of training is provided to which staff regarding the care of HIV positive women?
- How does the agency plan for the changing needs of women over time, as both the disease and the epidemic changes? How does the agency respond to such changes as they occur?

## **II. EVALUATION OF HOW WELL THE NEEDS OF WOMEN AS WOMEN ARE BEING MET BY CARE ACT FUNDING**

### **A. Type of Study/Methodology**

- Survey sample of HIV positive women from medical providers who provide HIV treatment or from primary care providers who recommend HIV testing to women
- Could be supplemented from street outreach programs

### **B. Issues to be Explored**

- In places where there are services tailored to women, what are the characteristics of the women accessing them?

- Do certain women go to one hospital or set of support services?
- What are women's experiences around access to drug treatment and other services, e.g., clinical trials?
- Where prescription drugs are funded by the CARE Act, what percentage go to women?
- What are the factors that facilitate use of the care system by women?

### **III. EVALUATION OF HOW WELL THE NEEDS OF WOMEN AS WOMEN ARE BEING MET BY CARE ACT FUNDING**

#### **A. Type of Study/Methodology**

- Focus groups of symptomatic and non-symptomatic HIV positive women
- Separate out symptomatic and non-symptomatic women
- Select from different geographic areas to identify regional differences, ethnicity. Include urban (high prevalence and low prevalence areas) and rural areas.
- Where possible, stratify by ethnicity

#### **B. Issues to be Explored**

- Women's familiarity with existing services
- Women's use of the system and barriers within the continuum of care-- detection, counseling, treatment, and support
- Personal, institutional, and social variables
- Why women drop out of services
- What are the crisis points in terms both of disease progression and other life events
- What are the changing needs of women

## Appendix A

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## Appendix B

### **THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY ACT OF 1990**

#### **Public Law 101-381**

The purpose of funds awarded under the Ryan White CARE Act are to assist in the delivery of essential services to individuals and families with HIV disease. This broad purpose is inclusive of all individuals, regardless of race, cultural or ethnic background, gender, or income. Nevertheless, some citations in Titles I and II of the CARE Act are specific to women, as follows:

#### **TITLE I**

##### **Section 2602: Administration and Planning Council**

(b) HIV Services Planning Council: This Council must include representatives of 11 discrete groups. One of these groups is "affected communities, including individuals with HIV disease." Women are an affected group in every eligible Title I city, but represent particularly high percentages in a number of metropolitan areas.

##### **Section 2603: Type and Distribution of Grants**

(b) Supplemental Grants: In applying for supplemental grants, eligible metropolitan areas must supply documentation on five specific areas, including "that resources will be allocated in accordance with the local demographic incidence of AIDS including appropriate allocations for services for infants, children, women, and families with HIV disease."

#### **TITLE II**

##### **Section 2612: General Use of Grants**

(b) "A State shall use not less than 15 percent of funds allocated under this part to provide health and support services to infants, children, women, and families with HIV disease."

### **Section 2613: Grants to establish HIV Care Consortia**

After defining consortia, this section enumerates essential health and support services to be provided through such consortia. Among the support services which may be assisted are "child welfare and family services (including foster care and adoption services)." Further, this section requires that before consortia may receive funds, they must assure the State that they have identified populations of HIV infected individuals and families to receive care, have a plan addressing the special care and service needs of these populations, and that service delivery to these populations will be integrated. An additional consortium may be funded in the area if it is demonstrated that this body will serve "subpopulations" existing within the community with unique service requirements that cannot be adequately and efficiently addressed by a single consortium serving the entire community or locality.

To receive Title II funding from the State, consortia must demonstrate in their applications that they include organizations representative of populations and subpopulations affected by HIV disease in the area to be served; that they have adequately planned to meet the special needs of families with HIV disease, including family centered care. The law then defines family centered care as "the system of services ...targeted specifically to the special needs of infants, children, women, and families. Family centered care shall be based on a partnership between parents, professionals, and the community designed to ensure an integrated, coordinated, culturally sensitive, and community-based continuum of care for children, women, and families with HIV disease."

### **Section 2618: Distribution of Funds:**

#### **Special Projects of National Significance (SPNS)**

Title II requires that 10 percent of the funds appropriated to the Title be used for a competitive grant program of Special Projects of National Significance (SPNS). These SPNS grants are to be awarded based on effectiveness of various proposed models of HIV care, innovations of proposed activities, and the ability to replicate SPNS supported projects in other areas. Such special projects may, according to the Act, include projects that are designed to "provide support and respite care for participants in family-based care networks critical to the delivery of comprehensive HIV care to the "minority community," to the hemo-

philia community, to "Indians with HIV disease and their families", to "individuals and families with HIV disease located in rural areas", and to "homeless individuals and families with HIV disease".



## Appendix C

### **SUMMARY OF PREVIOUS FEDERAL RECOMMENDATIONS SPECIFIC TO WOMEN AND HIV**

During the last two years, agencies of the Public Health Service, including the Health Resources and Services Administration, have sponsored and participated in a number of meetings designed to address the particular concerns of women and HIV. These meetings have produced a series of recommendations, many of which are pertinent to any discussion of access to care, and barriers to that access, for women living with HIV disease. Recommendations related to possible research agendas on care access are summarized below.

#### **FROM: PHS PANEL ON WOMEN, ADOLESCENTS, AND CHILDREN WITH HIV INFECTION AND AIDS DRAFTED DECEMBER 10, 1990**

**Goal 2: Increase the participation of women in advisory roles.**

*Discussion:* Women need to be included as advisors at every level of decision making about women's health and AIDS. A thorough review of women's participation in AIDS and HIV related activities, from programmatic levels to advisory bodies, needs to be conducted. Efforts must be made to include women in the design of and decisions on AIDS-related programs. Among the challenges and obstacles to this goal is the perception that few women exist who can fill key decision making roles and that differing interests are competing for the same small number of women. There is also a misperception that decisions made for the "general good" also specifically address and include the sensitivities or needs of women.

**Goal 3(b): Reduce HIV transmission to women through drug use**

*Discussion:* We must ensure that drug-abusing women have access to drug abuse treatment and that outreach and HIV prevention is focused also on women drug users not in treatment and on women whose partners use

drugs. Among the challenges and obstacles is the perception that drug abuse and HIV are separate problems that compete for the same, limited financial and staff resources.

Of particular interest to those involved in care issues are the following "needs" addressed under this goal: "Within the next 12 to 24 months, the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA), the Centers for Disease Control (CDC), and the Health Resources and Services Administration (HRSA) work together to identify and monitor the progress of efforts to make drug abuse treatment more accessible to women; ensure that all drug abuse treatment programs provide HIV prevention and education information that effectively reaches women. Monitor NIH/ADAMHA efforts to increase participation of women drug users and partners of drug users in clinical trials." And, "Need to articulate and focus upon the intersection of drug abuse prevention/treatment and HIV prevention and treatment and its impact on women; need to work closely with ADAMHA to support its overall efforts to improve drug abuse treatment for women."

**Goal 4: Ensure that women with HIV infection or at risk for HIV receive family-centered, community-based health care, including preventive care, for all HIV-related needs ranging from primary prevention to full care.**

*Discussion:* The U.S. health care system is frequently insensitive to the full range of health care needs of women. Men were the initial group to have AIDS, and the majority of current AIDS care programs have been serving men. The recent rapid increase of HIV incidence in women calls for the development of comprehensive health care programs that serve women, that provide childcare, or that offer women and children's health clinics in the same place. Limited resources and competing demands are challenges to this goal.

Among the specific action steps proposed were:

- (1) "identify and publicize innovative and effective health care programs that provide HIV-related services for women," and
- (2) identify barriers that still exist to such health care for women. Identify actions to take to remove those barriers."

**Goal 5: Continue to support the development of on-going professional education for health care providers. A special emphasis should be placed on the differing clinical spectrum of disease in women, disease course, and social and familial needs of women.**

*Discussion:* Understanding of the clinical course of the disease has focused for the most part on the documented history of the disease in men. Clinical case definition, treatment course, and expected outcome standards, for example, have not always been based on equivalent studies in women. The recent rapid increase of HIV incidence in women and the increased awareness of the differing impacts on women call for a continuing need to educate health care professionals. The education of health care providers in these potentially differing clinical manifestations of HIV infection and AIDS in women would allow for earlier diagnosis and treatment. Meeting this critical goal requires: the identification of all such clinical conditions that may be indicators of HIV disease; the design of appropriate training materials; periodic updates of information; and appropriate dissemination of this information.

**FROM: RECOMMENDATIONS FOR RESEARCH ON  
WOMEN AND HIV INFECTION  
NATIONAL CONFERENCE ON WOMEN AND HIV  
INFECTION HELD DECEMBER 1990**

This conference was sponsored by the agencies of the Public Health Service. After the conference, recommendations for further research were developed by a core group of community health care providers, advocates, women with HIV infection, researchers, and PHS representatives. The resulting drafts were circulated among additional community members for comments, which were then incorporated into the final draft. Recommendations were made available to PHS agencies for use in planning programs and research. The following recommendations relate to access to care.

**GENERAL RECOMMENDATIONS**

3. Support research that incorporates such characteristics as: participation of women in clinical drug trials and HIV/AIDS research; partnerships with community organizations, community advisory boards, community updates of research progress, and community feedback mechanisms; integrated research, treatment, and sup-

port services (for example, case management, transportation, and childcare); and community-based and street outreach to enroll women in clinical and prevention studies. Representatives of the population being studied should be included on the research team.

8. Establish a mechanism for development of collaborative activities, partnerships, and initiatives on HIV in women involving: patient advocates, PHS staff, researchers, physicians, and "front line" health and social service providers.

10. Establish a national clearinghouse on women's health to educate the public, collect and disseminate resource information, and provide an updated directory of ongoing research activities and community programs on all aspects of women's health including HIV/AIDS.

## **BIOMEDICAL/BEHAVIORAL/PSYCHOSOCIAL RECOMMENDATIONS**

### **Treatment Service and Research Needs:**

- a. Include gender-specific clinical assessments (e.g., pelvic examination, Pap smears) as part of the routine evaluation of an HIV-infected woman's medical status; as more is learned of the female-specific manifestations of HIV, new treatments should be developed and tested in a timely manner.
- b. Review clinical trial eligibility criteria in on-going studies; specifically, inclusion/exclusion criteria which may be too restrictive and thus prohibit participation of women (e.g., definitions of active drug use, pregnancy, anemia, elevated liver enzymes, etc.)
- c. Evaluate and develop clinical trial recruitment and retention procedure to facilitate enrollment and follow-up of women (e.g., access to primary medical care, child care, transportation to clinic sites, as well as other support services).
- d. Develop inexpensive, accessible therapeutics which can be used reliably by women who must frequently manage multiple responsibilities (e.g., family, job) despite declining health.
- e. Improve women-centered HIV case-finding activities with effective counseling (including asymptomatic individuals) in various settings (e.g., prisons, emergency rooms, other institutions) that are directly linked to

medical and social services. Employ street and community outreach for HIV case-finding.

f. Determine the extent of health care service needs for HIV-infected women, especially women with multiple medical (including chemical dependency) and psychological diagnoses, to improve access, coordination and quality of care.

g. Further investigate determinants of health care seeking behavior in women, including study of the role of social networks/support systems in facilitating women's access to services.

## **PHS ACTION PLAN FOR WOMEN'S HEALTH**

**Published September 1991**

This plan is not exclusive to HIV in women but represents a reaffirmation of the PHS commitment to women's health as a national public health priority. Structured along PHS agency lines, the document contains initiatives for women's health formulated in goals and mileposts by Agencies, offices of the Assistant Secretary for Health, and in a series of appendixes, one of which is crosscutting issues. In the latter, AIDS/HIV as a Women's Health Issue is one of three issue areas addressed. The following material has been abstracted from the HRSA section of the document, the AIDS/HIV appendix, and other pertinent areas.

### **HEALTH RESOURCES & SERVICES ADMINISTRATION**

#### **Goal: Training**

*Action step 1.* Establish ongoing relationships between HRSA and NIH to ensure that current information concerning the clinical manifestations of HIV infection and AIDS in women is transferred rapidly from NIH to HRSA/BHPr's AIDS Regional Education and Training Centers (ETC) Program grantees. The ETCs will, in turn, ensure that the information is available to health care providers in their area and that it is incorporated into the ETCs AIDS educational offerings (spring 1991).

#### **Goal: Services, Treatment – BHRD**

To ensure that the grantees funded under the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 appropriately develop and make accessible

services for women with HIV/AIDS as part of a continuum of health and support services.

**Need:** According to the CDC, cases of AIDS among women increased by 49 percent in the past fiscal year, while cases among men rose by 39 percent. Cases among women are attributed primarily to intravenous drug use and to heterosexual contact with male drug users. Over the next 24 months, attention will focus on a critical women's health issue -- that is, the likelihood of underreporting of AIDS cases that might be concealing an even higher percentage of infected women.

**Challenges or Obstacles:** An increasing emphasis must be on HIV/AIDS education and early intervention. Women may be less likely to go to AIDS clinics because many believe clinics are geared toward gay men. Health promotion activities should be made available in any setting where women receive routine or emergency health care.

### Long-Term Objectives

- Achieve an equal focus of HIV/AIDS services delivery to men and to women through FY 1992 as a part of this PHS Action Plan. As the statistical trends indicate, an increasing incidence of HIV/AIDS in women should prompt HRSA grantees to be active in expanding and improving services to women.

**Accomplishments within 12 to 24 months:** Based on established program reporting requirements for CARE grantees, HRSA will analyze how grantees responded to the service needs of women. The HRSA will be able to estimate annually how many of the clients served by each grantee were women and to track trends in services for women over time.

The CARE grantees will submit narrative reports annually regarding their grant activities and accomplishments, including their impact on service delivery to women infected with HIV/AIDS. (Expansion of Community Health Center/ Migrant Health Center(C/MHC) perinatal activities through the Comprehensive Perinatal Care Program will assist in identifying HIV-positive/at risk women and provide education, early identification, and intervention.)

### **Action Steps and Mileposts**

1. Establish program priorities to address requirements that Title II State plans specify how programs addressing special needs of women, children, and families are to be ranked and funded.
2. Applications will undergo objective review with criteria that include effects on women.
3. First year reports (due February 1992) will be required to document effects on women in each grantees' service delivery area.

### **Goal: Services, Treatment – BHCDA**

Among the action steps for this goal are several that link with the BHRD goals:

- In C/MHCs, homeless projects, and other BHCDA funded primary care programs, identify and implement innovative ways to encourage women to seek health care and to provide primary health services to the hardest-to-reach women (i.e., providing primary care in homeless shelters, AIDS education in jails, immunization/ mammography clinics in housing projects).
- Increase the availability of effective AIDS interventions to ethnic minority and underserved women to reduce primary and secondary transmissions of HIV/ AIDS.
- Support demonstrations under Ryan White legislation in collaboration with State and local health departments and local providers to integrate outreach, education, and counseling services with primary care and substance abuse treatment.

## **THE NATIONAL INSTITUTES OF HEALTH RESEARCH FRAMEWORK RELATED TO WOMEN AND AIDS 1991-1992**

- National Conference on Women and HIV Infection: A major national conference brought together providers, investigators, and women with HIV infection to address research needs, up-to-date treatment information, social and economic barriers and their effect on research, and community and educational resources (December 1990)
- Women's Health Committee of the AIDS Clinical Trials Groups (ACTG). This committee has been established to ensure that women's issues become an

integral part of the AIDS research agenda, to work to implement priority trials initiatives, to increase enrollment of women in ACTG trials and to provide information about resources required to recruit and retain HIV-infected women in these studies, to ensure that assessments of women in trials include evaluations of their gynecologic status relevant to the therapy under trial, to increase knowledge about the safety and efficacy of therapeutics in HIV-infected women, and to collaborate with pediatricians in perinatal transmission trials because studies of pregnant women are regarded as the simultaneous study of drugs in two patients.

- The Women and Infants Transmission Study (WITS) and the Heterosexual HIV Transmission Study (HATS): both epidemiologic studies will be expanded to increase the understanding of HIV in women.
- Initiate a feasibility phase of an epidemiologic study of perinatal transmission of HIV-2 (1991).
- Initiate an epidemiologic study of the effect of HIV on cervical dysplasia and/or carcinoma in the Caribbean (1991).
- Trials of recombinant CD4 protein given at the time of labor and delivery to abrogate maternal-fetal HIV transmission/infection will be expanded.
- Effective use of condoms can protect women from HIV transmission. Research will be supported on behavioral aspects of condom use; development of new condoms from polyurethane, which is less likely to tear or deteriorate; and clinical efficacy and acceptability of polyurethane condoms.

#### **OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH NATIONAL AIDS PROGRAM OFFICE (NAPO)**

**GOAL:** To use the relationship between NAPO and PHS Regional AIDS Coordinators to facilitate the distribution of up-to-date information on women and AIDS to the Regions and States.

**GOAL:** To enhance exchange of information between community-based organizations and public constituency groups and NAPO. This exchange is a critical step to get the input of front-line organizations on issues specific to women and AIDS in the community.



## Appendix D

### **CROSS CUTTING ISSUES AIDS/HIV AS A WOMEN'S HEALTH ISSUE**

Clinical case definition, treatment course, and expected outcome standards have been based on the history of the disease in men. Most HIV-infected women are of reproductive age who have to make decisions about their reproductive lives. Decisions to prevent pregnancy, together with the need to prevent HIV transmission need to be supported by the availability of safe and effective methods of contraceptives.

Services for ensuring access to contraceptive alternatives are incomplete and may lack coordination with HIV services. Program models need to be developed and evaluated to ensure access to contraceptive services.

Women at highest risk for acquiring HIV--drug users, members of poor, underserved ethnic minority communities--may be the most difficult to reach, enroll, and retain in traditional treatment, prevention, and research studies. Special efforts need to be undertaken to reach women at high risk, especially inner city minority women residing in communities with large pools of HIV infection. Treatment and prevention approaches responsive to the realities of their lives need to be developed and evaluated.

Knowledge about how to treat women with AIDS is lacking. HIV clinical guidelines for primary practitioners need to be developed and disseminated. Because of the rapid scientific breakthroughs being made in the treatment of HIV, such guidelines need to be kept current and need to address the unique health care needs of women with HIV infection, such as vaginal candidiasis and increased risk of cervical dysplasia.

Two-way communication between the clinical investigator and those rendering care to the HIV infected women is essential to ensure adequate access to clinical trials for women. An active research-care interface is needed to

ensure that, when the clinical trials group identifies new strategies for treatment, the care givers of these women are promptly informed of the results of these trials.

Research needs extend also to studies aimed at understanding the economic and policy issues surrounding the financing of health care for women with HIV/AIDS, the barriers to their care, their functional status, and their quality of life.

Women who are HIV-infected are often under an additional burden: they are mothers, partners, and care givers, sometimes of others with HIV disease.





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